

Testimony to House Health Policy Committee regarding HB 5136:

Statewide Standard Consent Form for sharing Behavioral Health Information

Chairwoman Haines and members of the House Health Policy Committee,

Thank you for the opportunity to present testimony to you today.

By way of brief introduction, since November 2011, I have served as Associate Director for the Michigan Health Information Network Shared Services (MiHIN), a public and private 501(c)(3) not-for-profit mission-based collaboration operating under a charter established by Public Act. Our mission is improving the healthcare experience, improving quality and decreasing cost for Michigan's people by supporting the statewide exchange of health information and making valuable data available at the point of care. MiHIN was created in December 2010 to administer the technical and business operations of Michigan's State Health Information Exchange (HIE) Cooperative Agreement program through the Office of the National Coordinator for Health Information Technology (ONC).

Michigan has made significant progress in facilitating the adoption and use of electronic health information exchange (HIE) within the state and is increasingly viewed nationally as a leader due to our state's collective accomplishments. Under the HITECH Act's State HIE Cooperative Agreement, Michigan was awarded a Federal grant to assist in achieving statewide electronic exchange of health information. The Michigan HIT Commission has implemented measures and achieved significant progress in the state-wide adoption of electronic health records, the promotion of electronic HIE, and the increased utilization of other types of HIT such as the use of patient registries and electronic prescribing. The HIT Commission has been charged with, among other things, developing and maintaining a strategic plan for the HIE to include measures to protect the privacy and security of health information transmitted through the HIEs in Michigan. MiHIN has the responsibility for coordinating execution of this plan.

Beginning in January 2012, at the urging of MiHIN's Board member representing the Michigan Department of Community Health (MDCH), MiHIN formed a working group to focus on Security and Privacy. This was a remarkably forward-thinking recommendation. When I tell my friends, family, neighbors etc. what I do for a living and how the information passing through MiHIN's network could lower costs and save lives, they generally tell me that's all well and good, but then they tell me they are concerned about the privacy and the security of their health information.

The Security and Privacy Working Group viewed the relationships between security, privacy, and consent as follows:

Privacy: What information is to be protected

Security: <u>How</u> information is to be <u>protected</u>

Consent: Which information can be shared

In 2012 this group focused primarily on Security issues and produced a Cybersecurity White Paper containing various recommendations to improve security of the exchange of health information statewide and presented this to Governor Snyder's Health Information Technology Commission in early 2013 and then to Governor Snyder's Cybersecurity Task Force. In January 2013 MiHIN held the first of two workshops on Privacy attended by more than 40 persons and organizations from around the state concerned with Privacy issues surrounding the electronic exchange of health information. In April 2013 we held the second Privacy workshop where a number of Privacy issues and recommendations were formulated and are available in the materials we are supplying today in the form of our Draft Whitepaper on Privacy, to be finalized in March of this year.

At the April 2013 workshop the participants identified one Privacy issue that required immediate attention, which was called the "fast track" issue. This "fast-track" issue was the need for a standard consent form to be used statewide for Michigan residents to authorize and consent to the sharing of their Behavioral Health information. Patients must consent to the sharing of sensitive Behavioral Health information under a variety of existing federal and state laws, including Federal Substance Abuse (SA) Regulations 42 C.F.R and Michigan Mental Health Code MCL 330.1748.

As presented to the HIT Commission in July, 2013, the rationale for "fast tracking" the development of a standard consent for Behavioral Health (BH) information sharing included:

A highly fragmented status quo with high risks for privacy:

- No patient consent for BH HIE sharing
- Sharing gap between BH and Physical Health (PH) providers
- Multiple agencies implementing disparate processes and policies
- No standard practices to support integrated care coordination
- Further HIT fragmentation

A desired coordinated future outcome which greatly lowers privacy risks:

- BH providers utilize HIE to send and receive data
- Physical Health providers receive BH information
- Patients understand and benefit from sharing

eligibility would result in significant cuts to services, or discontinuation of services in some areas.

On January 20 and 23 we held meetings with Mary Lovik, a MDSVPTB staff attorney, and urgently formed a special sub-group to work with MDSVPTB staff to adjust our proposed standard form to accommodate VAWA requirements. We have not reached final resolution to all of the complex issues involved in information sharing and consent required to comply with VAWA but the first two meetings have been very positive and ideas are on the table that have the potential to successfully accommodate VAWA requirements in the standard consent form effort. One option we are exploring is a cautiously worded question on the primary standard consent form that could trigger a supplemental VAWA-compliant form. Alternatively, another option is to alter the proposed legislation to exclude cases in which the duty to honor and accept the standard form conflicts with the requirements of federal statutory, regulatory, or contractual provisions, but this could result in numerous special case forms and defeat the purposed of having a standard form. A workable compromise is to have a standard basic form that could be augmented by supplemental pages that treat special cases such as VAWA's requirements for protecting the privacy of victims of domestic and sexual abuse.

Whether legislation is enacted or not, a statewide standard consent form for Behavioral Health information sharing is the right thing to do and should be pursued in any event. However, legislation would accelerate the rate of adoption, would help prevent "splinter" efforts, and would especially assist with the statewide education and awareness requirements that the HIT Commission identified in September that would result in the adoption of a statewide standard consent form. It is extremely important that this education and rollout be carefully planned and executed, and the new co-chair of our Privacy Working Group, John Donovan of the Department of Technology, Management, and Budget (DTMB) has already begun drafting a framework for an education and awareness plan. In addition to legislation having strong value in its ability to accelerate the rollout and adoption of a standard consent, it is important to leave room to experiment and learn as the technology and work process matures.

Here is a quick example of where the technology must still mature. The information technology vendors implementing electronic consent forms have concerns about taking a paper form and translating it into an electronic process. There are some complex technical challenges related to an issue called **data segmentation**. Data segmentation is "the process of sequestering from capture, access, or view certain data elements that are perceived by a legal entity, institution, organization or individual as being undesirable to share," and a link to a good summary of this problem is:

http://library.ahima.org/xpedio/groups/public/documents/ahima/bok1_050014.hcsp?dDocName=bok1_050014.

While national efforts such as pilots last year with the Department of Veterans Affairs are making progress on technology solutions to the data segmentation problem, the challenge associated with creating a solution that works both as a paper form and in an electronic

- Creates the platforms for implementing integrated care
- All providers deliver integrated care for their shared patients
- Functioning consent solution

We presented progress updates to the HIT Commission at their August and September meetings. In September 2013, thanks to Lynda Zeller of MDCH, we learned of the efforts of the Honorable Judge Curtis Bell and the Diversions Council under the Lieutenant Governor to produce a standard consent form for use in Corrections situations. Through an intern from Cooley Law School working with Judge Bell and the Diversions Council group we were able to to coordinate our efforts by a series of meetings whereby the common goal of a standard statewide consent form for behavioral health information sharing drove us into a mode of highly focussed cooperation to combine into one team and one form.

On January 9th and 10th of this year, members of the Privacy Working Group and the CIO Forum held meetings with representatives of the Diversions Council group working with Judge Bell and we successfully reduced a "Baker's Dozen" list of differences between the two proposed standard consent forms into a short list of two relatively small remaining open issues. The two groups are now operating as one, and we are consolidating the two proposed consent forms into one. We are optimistic that we can arrive at a mutually-agreed draft standard consent form for Behavioral Health information sharing that can be presented to MDCH for consideration for adoption. On February 3, representatives from the CIO forum, the Diversions Council, and the Privacy Working Group met again and reached mutually agreed proposed solutions on the remaining differences between the two forms which are being consolidated into one combined draft with at least one major issue remaining open.

On January 13, Judge Bell provided information from legal staff at the Michigan Domestic and Sexual Violence Prevention and Treatment Board, Michigan Department of Human Services, alerting us to the need to accommodate conditions of eligibility for recipients of grant support under the federal Violence Against Women Act (VAWA), 42 USC 13925(b). Michigan governmental and private non-profit agencies currently receive nearly \$5.5 million in VAWA funding. VAWA funding supports Michigan law enforcement efforts, including a sexual assault cold-case unit in the Attorney General's office, and training for police officers and prosecutors statewide. A significant portion of this funding also supports private, non-profit agencies that provide counseling, crisis intervention, emergency shelter, and various advocacy services for victims of domestic and sexual violence in every Michigan county. To be eligible for VAWA funding, victim service agencies must comply with strict statutory provisions for protecting victim privacy that are intended to prevent sensitive locating or personal information from finding its way into the hands of abuse perpetrators or others who would make malicious use of it. VAWA requires releases of victim information to be informed, written, and time-limited. The federal Office on Violence Against Women within the U.S. Department of Justice has provided guidance that "informed consent" includes a highly specific description of the type of information shared and the purposes for the sharing. If VAWA-funded programs were obliged to honor and accept a form that does not comply with these requirements, the loss of funding

environments is non-trivial and very important. Legislation could serve to compel vendors to advance the solution timetable for challenges like this one.

We want to leave you with the following important point. The proper management of privacy and patient consent for health information sharing is a complex multi-year issue that potentially affects many diverse groups and we are just beginning to work through the broad landscape of privacy issues. Encouragingly, we started with one of the most difficult aspects, behavioral health consent, and have made great strides forward under the combined leadership of Judge Bell, the Diversions Council and the CIO Forum. Much work remains across the entire privacy spectrum, but we already have an excellent start in the right direction with tremendous positive involvement from stakeholders statewide to get very close to a workable standard consent form.

In closing, today we are pleased to provide copies of this testimony, our draft Privacy White Paper, and our October 2013 presentation to the HIT Commission as background for you and your staff members. The additional materials listed in Addendum A are also available for your staff members upon request.

We wish to express our appreciation to the many contributors and organizations that have participated in our efforts on Privacy, including the 2013 Privacy workshops, the draft Privacy White Paper and the draft standard consent form for sharing Behavioral Health Information, more than 35 contributing organizations listed in Addendum B. The general categories of Privacy issues and draft recommendations from our draft Privacy White Paper which reach beyond the fast-track standard Behaviorial Health consent issue are listed in Addendum C.

Thank you for your valuable time and the opportunity to present this testimony on Privacy in health information exchange within Michigan.

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Addendum A - List of Privacy and Security Documents Available from MiHIN on Request

- 1. Current draft of work-in-progress consolidated standard consent form sharing Behavioral Health Information (goal is to finalize by March 13, 2014, to present to March 20 meeting of Health Information Technology Commission)
- 2. Presentations on Privacy to Governor Snyder's HIT Commission:
 - a. July 2013 introduction of "fast track" consent issue to Commission
 - b. August, 2013 update to Commission
 - c. September, 2013 update, discovery of Diversions Council efforts
 - d. October, 2013 update and plan to consolidated forms into one
- 3. Final Draft Privacy White Paper (survey on priorities is underway; ETA 03-14)
- 4. Final Cybersecurity White Paper and Prioritized Recommendations (completed 2013)

Addendum B - List of Organizations Participating in Privacy Efforts with MiHIN

Bay/Arenac Behavioral Health Authority

Southeast Michigan Beacon Community (SEMBC)

Blue Cross Blue Shield of Michigan

Carebridge

CIO Forum (Behavioral Health CIOs)

Clinton- Eaton-Ingham Community Mental Health Authority

Detroit Wayne Community Mental Health Authority

Dickinson-Wright Law Firm

Diversions Council

Great Lakes Health Information Exchange (GLHIE)

Ingenium

Jackson Community Medical Record (JCMR)

Kalamazoo Community Mental Health & Substance Abuse and Services

Macomb County Community Mental Health Agency

Michigan Department of Community Health (MDCH)

MDCH Recipient Rights Group

Michigan Department of Human Services

Michigan Domestic and Sexual Violence Prevention and Treatment Board

Michigan Health & Hospital Association (MHA)

Michigan Health Connect (MHC)

Michigan Health Information Technology Commission

Michigan Health Information Management Systems Society (MI-HIMSS)

Michigan Health Information Network Shared Services (MiHIN)

Michigan Mental Health Diversion Council Michigan State Medical Society (MSMS)

Netsmart

Oakland County Community Mental Health Authority (OCCMHA)

PCE Systems

Provider Alliance of the Michigan Association of Community Mental Health Boards

Southeast Michigan Health Information Exchange (SEMHIE)

Health Section of the State Bar of Michigan

State of Michigan Department of Technology Management and Budget

Summit Pointe

The Standards Group/CIO forum

Upper Peninsula Health Information Exchange (UPHIE)

Venture Behavioral Health

Washtenaw Community Mental Health Authority

Addendum C – Summary of Draft Privacy White Paper Recommendations Privacy Consent

1. Create a statewide standard consent form, standard consent language, and consent use cases for behavioral health [the "fast track" issue subject to proposed legislation]

Privacy Awareness and Education Areas

- 2. Develop an education and training program with privacy awareness curriculum to provide a clear understanding of privacy obligations and the need for policies and procedures designed to meet those obligations
- 3. Coordinate privacy awareness training with security awareness
- 4. Direct an entity designated by the State to develop an attestation document for organizations to affirm that comprehensive privacy policies and procedures have been documented, adopted, implemented, and enforced
- 5. Direct an entity designated by the State to develop and conduct an auditing program to confirm that organizations engaged in health information exchange have adopted and properly implemented policies and procedures for compliance with applicable privacy laws and regulations

Risk Identification and Management

- 6. Clarify the nature of the legal risks associated with a violation of each pertinent privacy law or regulation, and their potential application to an HIE or a Participant
- 7. Direct an entity designated by the State to provide guidance regarding existing or recommended federal and state "safe harbor" conditions that may apply to the operations of HIEs and that may insulate HIEs, Participants, or both from liability under applicable privacy laws and regulations
- 8. Direct an entity designated by the State to provide guidance as to when HIEs must respond to violations of privacy laws that are known to the HIE, or that are disclosed by HIE Participants, and create standardized responses that should be used by HIEs in such event
- 9. Direct an entity designated by the State to determine the terms and conditions for data exchange between the HIEs and the Veteran's Administration and other Federal entities

Patient Consent and Authorization

- 10. Direct an entity designated by the State to determine the specific consent/authorization rules with respect to the transmission of PHI, each type of OHI, or Patient Health Records
- 11. Direct an entity designated by the State to create a standard framework around the transmission of PHI and each type of OHI through the HIE that is consistent with the rules identified in Section 5.1, and the HIE's role with respect to facilitating the framework. This might include the development of standard consent forms to be used by Participants (e.g., "all- in", "all-out", and "check the box" consents)
- 12. Direct an entity designated by the State to investigate and recommend a technical framework/architecture to enable the implementation of the adopted consent regimen. This might include investigation into the necessity of data segmentation in HIEs relating to OHI (or what information must be defined for data segmentation) and the appropriate methods to effectuate such data segmentation

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